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ABSTRACT

The Individuals with Disabilities Education Act (IDEA) requires that each state participating in the federal early intervention program establish a state interagency coordinating council (ICC) to assist and advise the state lead agencies in achieving a coordinated service delivery system. When IDEA was reauthorized in 1991, by the passage of P.L. 102-119, it mandated that at least 20 percent of the members of each ICC be parents of children with disabilities. This documents reviews and answers the questions most frequently asked by new parent ICC members. It is intended to be an introduction for parent members as they become familiar with the workings of the ICC. Questions answered include: (1) What is the Interagency Coordinating Council and how does it relate to young children in my state? (2) What can I read to help me understand the law? (3) Who else serves on the ICC? (4) Should I contact past parent members? (5) Are there local ICCs, what is their role, and how do we communicate with their members? (6) What information should I get about my ICC? (7) What is my role on the ICC? (8) What is NECTAS and how can it help me as an ICC member? A list of introductory resources is included. (SG)

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COALITION QUARTERLY

EARLY CHILDHOOD BULLETIN

PRIMER FOR NEW ICC PARENTS

By

TERRY OHLSON

FALL/WINTER

1991-92

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Coalition Quarterly

EARLY CHILDHOOD BULLETIN

News by and for Parent Members of State Interagency Coordinating Councils

Fall/Winter Prepared by NEC*TAS Parent Component Staff • Janet R. Vohs, Editor 1991 - 92

Primer for New ICC Parents

By Terry Ohlson, Resource Specialist
Parent Information Center, New Hampshire

Terry Ohlson is a staff member at the Parent Information Center (PIC) in Concord, New Hampshire, a federally funded Parent Training and Information (PTI) center. At the time she wrote this article, Terry was just completing three years as a Parent Resource Specialist for the National Early Childhood Technical Assistance System (NEC*TAS). She is now a Parent Resource Specialist for the Collaboration Among Parents and (Health) Professionals Project, a National Parent Resource Center funded through the U.S. Department of Health and Human Services, Bureau of Maternal and Child Health.

Terry and John Martin reside in Webster, New Hampshire, with their four children, Kenny, who has cerebral palsy, Jimmy, Heidi and Rachel.

When the Individuals with Disabilities Education Act was reauthorized in October, 1991, by the passage of P.L. 102-119, it mandated that at least 20% of the members of each state Interagency Coordinating Council (ICC) be parents of children with disabilities. These questions are among those frequently asked by new parent ICC members. The answers are intended as an introduction for parent members as they become familiar with the workings of the ICC.

What is the Interagency Coordinating Council? How does it relate to young children in my state?

Part H of the Individuals with Disabilities Education Act was originally passed in October 1986 as P.L. 99-457, one of the amendments to the Education for All Handicapped Children Act (EHA) when it was reauthorized that year. Part H established a new program to permit and encourage states to begin establishing comprehensive, statewide systems for providing early intervention services to infants and toddlers with disabilities or at risk of disability. Each state participating in the federal early intervention program was required to establish an ICC to "advise and assist" the designated lead agency.

The law is designed to foster a coordinated system of services that, when fully operational, would be available to *all* eligible children and families in the state. The reason for establishing such an interagency body was to foster linkages and coordination among the many agencies providing services. As an independent group, the ICC would not belong to any one agency and there would be a greater chance that the individual groups would contribute to the development of a system of interacting services. The independent nature of the ICC is one feature that gives it the potential for making a contribution to the development of the service system.

In addition to the parent members, the ICC has representatives from professional disciplines, state agencies, and provider organizations. The federal legislation specifies what types of members should be included on the ICC to ensure that the design of the service system reflects a vision informed by the perspectives of families and the clinical, political, and administrative communities.

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What can I read to help me understand the law?

Reading the law itself is always a good idea. While some sections contain information that is primarily of use to state agencies administering the program, the actual substance of the law is not that long or difficult to read, especially those sections which deal with why the law was written ("findings"), definitions, the IFSP, and, of course, the State Interagency Coordinating Council. The law *is* the law; you ought to read it. When Part H, along with other sections of IDEA, was reauthorized in October 1991, many changes were made in response to the testimony of parents to Congress.* These amendments are now part of the law.

Accompanying these amendments was House Report 102-198. This Congressional Report contains an overview and discussion of all the changes that were made, and then gives a section-by-section analysis of them, all in very readable language. It gives some of the history and reasons for the changes made. Your state ICC or the lead agency in your state should have copies of the original law. Finally, it is important to note that the Regulations guiding implementation of the new law are not yet issued, but will be an important reference document for all ICC members. Future issues of the *Early Childhood Bulletin* will notify readers when they are available. NEC*TAS is also available to provide information on technical matters. Some basic introductory resources are listed below:

- Copies of P.L. 102-119 and the accompanying House Report (#102—198) can be obtained through contacting your member of Congress or from the House Documents Room, Room B-18, House Annex #2, Washington, D.C. 20515.
- *The Complete Individuals with Disabilities Education Act*, compiled as of October 7, 1991, (which includes changes from the most recent reauthorization) is available from LRP Publications for $9.95. For more information, call LRP at (800) 341-7874.
- Gerst, D., Holden, L., Norwood, C., Sykes, D. (1991) *Go Ask Alice: A Guidebook for Parents Serving on State and Local Interagency Councils: Eight parents who have served on state ICCs for early intervention share their experiences and insights.* Ohio State University Research Foundation: Columbus, Ohio.

  This book documents real-life experiences of parents who served on Councils, offers a framework for thinking about the issues, and discusses the roles of parents and current challenges ICCs face. To order, contact the Early Intervention Training Project, 700 Ackerman Road, Suite 440, Columbus, Ohio 43202; (614) 447-0844. Copies may be ordered at $6 each, plus 10% of the total for shipping and handling.
- McGonigel, M.J., Kaufmann, R.K., Johnson, B.H. (1991) *Guidelines and Recommended Practices for the Individualized Family Service Plan, (2nd Edition).* Bethesda, MD: Association for the Care of Children's Health.

  A third edition, revised and updated by ACCH and NEC*TAS to reflect the recent changes, will be available by April 1992. To order, contact ACCH, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814; (301) 654-6549. Cost is $15 plus $3 for shipping and handling.
- Shelton, T.L., Jeppson, E.S, and Johnson, B.H. (1987) *Family-Centered Care for Children with Special Health Care Needs. (2nd Edition).* Bethesda, MD: Association for the Care of Children's Health.

  This book distinguishes and illuminates the essential features of family-centered care, giving practical applications to one of the most important principles that should be guiding the design and provision of early intervention services for children and families. It is not about the law *per se*, but about an approach to serving children and families that is family-centered as required by the law. A revised and updated version of this volume will be published in Spring 1992. To order, contact ACCH, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814; (301) 654-6549. Cost is $15 plus $3 shipping and handling.

Who else serves on the ICC?

Your ICC must include parents of children (birth through 12 years) who have disabilities, including a parent of a child under the age of six; providers of early intervention services; a state legislator; a person involved in personnel preparation; and people representing other agencies who provide or pay for early intervention services including the state agency governing insurance. States vary in the number of ICC members, and may include people in addition to those listed above. However, according to Part H, the minimum number of members should be 15 and the maximum number should be 25. Of those members, at least 20% must be parents of children

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* Terry Ohlson has written a summary highlighting major changes in Part H that are of particular interest to families. Space limitations did not allow the summary to be included as part of this *Early Childhood Bulletin*. For more information, interested readers may contact Janet Vohs, Editor, Federation for Children with Special Needs, 95 Berkeley Street, Boston, MA 02116; (617) 482-2915.

with disabilities.

The ICC chair may be appointed by the Governor or the Governor may authorize the Council to select a chairperson. Officially assigned agency representatives may send a replacement to represent them at meetings. If you do not already have a list of ICC members with names and addresses, ask the chair for one.

It may be helpful to talk with each member individually to get a clearer idea of who is representing what and to learn how they see their role on the ICC. Meeting individual ICC members may also help you to understand the working of the ICC.

Should I contact past parent members?

Past parent members can offer you several things: a history of the ICC; a perspective on what has and has not been done by the ICC and why; ideas on how to be most effective in your work on the ICC and with individual members; ideas on how to represent parents, and how to maintain contact with parents throughout the state.

Your ICC chair should be able to give you a list of past parent members and how to contact them.

Are there local ICCs? What is their role and how do we communicate with their members?

Many but not all states have local or regional ICCs that support and provide information to the state ICC. Members are often family members, and can give you valuable insight on the effect your decisions have on their families. As a Council, they may also be working on local policy and procedures that will be directly affected by state policy and procedures. Talk with your ICC chair about the system in your state.

What information should I get about my ICC?

- Bylaws, rules and procedures. You need these in order to work properly and effectively with the Council.
- Any orientation materials, including mission statement, philosophy statement.
- Any materials developed by your ICC, including general informational materials, books, monographs, tapes. These will give you an idea of how the philosophy and mission of the ICC translates into practice.
- A list and descriptions of past and current projects funded by the ICC.
- Annual reports and minutes of past meetings, including committee meetings. These records will give you an idea of the specific work of the ICC and how it has evolved.

What is my role on the ICC?

As a parent member of the ICC, you are representing families in your state. As their representative you have a responsibility to be in contact with families across your state, and across disability, income, education, and ethnic and racial groups. The easiest way to do this is through contact with formal and informal parent groups which are already established. These groups would include disability specific organizations such as the Association for Retarded Citizens or Association for Community Living, and experience-specific groups such as NICU parents and organizations associated with programs or schools.

Each state also has a federally funded Parent Training and Information Center (PTI). These centers provide advocacy, information, and training to families of children with disabilities, and often collaborate with other family organizations. If you are not familiar with the PTI in your state, contact Evelyn Hausslein, the NEC*TAS parent contact at the Federation for Children with Special Needs.

*What is NEC*TAS and how can it help me as an ICC member?*

The National Early Childhood Technical Assistance System (NEC*TAS) is a federally funded program to provide technical assistance on the implementation of early intervention and preschool services under IDEA (Individuals with Disabilities Education Act). NEC*TAS works primarily with state Part H programs (early intervention), ICC chairs, state preschool programs, and community-based model projects of the Early Education Program for Children with Disabilities.

NEC*TAS also provides assistance specifically to parent members on ICCs in all states. In addition to providing information and phone consultation, NEC*TAS sponsors an annual meeting of ICC parent members, occasional conference calls on topics of interest to parent members, and this *Early Childhood Bulletin*.

For information about NEC*TAS or to request assistance, please contact Evelyn Hausslein, NEC*TAS, Federation for Children with Special Needs, 95 Berkeley St., Suite 104, Boston, MA 02116; (617) 482-2915. ■

Department of Defense to Provide Early Childhood, Early Intervention Services

By George Cibula, Parent Education Coordinator
Washington PAVE

Until recently the Department of Defense (DoD) school systems were exempt from the mandate to serve children under the age of five years. Department of Defense Dependents Schools (DoDDS) and the Section 6 Schools had limited preschool services for some children ages three to five. Because of the exemption these services were at times provided on a space available or limited basis. Therefore, many military children who were eligible for services were unserved or underserved.

Congress, in reauthorizing the Individuals with Disabilities Education Act, corrected this discrepancy. Both the House and the Senate introduced bills (S. 1106 and H.R. 3053) that included the DoDDS and Section 6 Schools in the mandate to provide services to young children with disabilities. The bills state:

> ...the provisions of part B of the Individuals with Disabilities Education Act (IDEA) shall apply to all schools operated by the DoD under this title, including the requirement that children with disabilities, aged three to five inclusive, receive a free appropriate public education by academic year 1993–1994.

It also contains the following provisions with regard to children ages birth to three in military families:

> ...the responsibility to provide comparable early intervention services to infants and toddlers with disabilities and their families in accordance with individualized family service plans (IFSPs) described in Section 677 of IDEA and to comply with the procedural safeguards set forth in Part H of such Act shall apply with respect to all eligible dependents overseas.

The timelines for carrying out these provisions for children birth to three insure that by the 1991–92 school year and the succeeding two years DoD will plan and develop a multidisciplinary program of early intervention services. In the academic year 1994–95 they must implement the program developed the previous years to the extent that they will be required to conduct multidisciplinary assessments, develop IFSPs and make case management services available. The program previously developed will be in effect in academic year 1995–96 and all succeeding years.

The joint resolution known as House Report 102–19[illegible] was signed by President Bush on October 7, 1991.

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Representation of parents in NEC*TAS (the National Early Childhood Technical Assistance System) has changed in the newly funded contract that began October 1, 1991. The four TAPP Regional Centers are no longer part of the project, but the Federation for Children with Special Needs, Boston, is continuing to participate in NEC*TAS. For information about activities involving ICC Parents, please feel free to call Evelyn Hausslein, Ruth–Ann Rasbold or Martha Ziegler at (617) 482–2915.

The "Early Childhood Bulletin" and *Coalition Quarterly* are mailed to over 500 parents and professionals involved in early intervention/early childhood education, including ICC parent representatives, Part H Coordinators, ICC Chairs, and Directors of state Sec. 619 preschool programs.

As the membership on the ICC changes, the NEC*TAS mailing list for these publications changes accordingly. If you are new to the ICC, please make sure your ICC chair has given us your name for inclusion on the mailing list.

If you are no longer on the ICC and wish to continue to receive these publications, you may do so by contacting Evelyn Hausslein, Federation for Children with Special Needs, 95 Berkeley St., Suite 104, Boston, MA 02116; tel. (617) 482–2915.

This Bulletin is prepared by the staff of the Federation for Children with Special Needs who participate in the National Early Childhood Technical Assistance System (NEC*TAS), which is funded through the U.S. Department of Education's Office for Special Education Programs (OSEP), Early Education Program for Children with Disbilities, under contract no. 300-87-0163 awarded to the Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill. Grantees undertaking such projects under government sponsorship are encouraged to express their judgment in professional and technical matters. Points of view or opinions, therefore, do not necessarily represent the Education Department's position or policy.

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